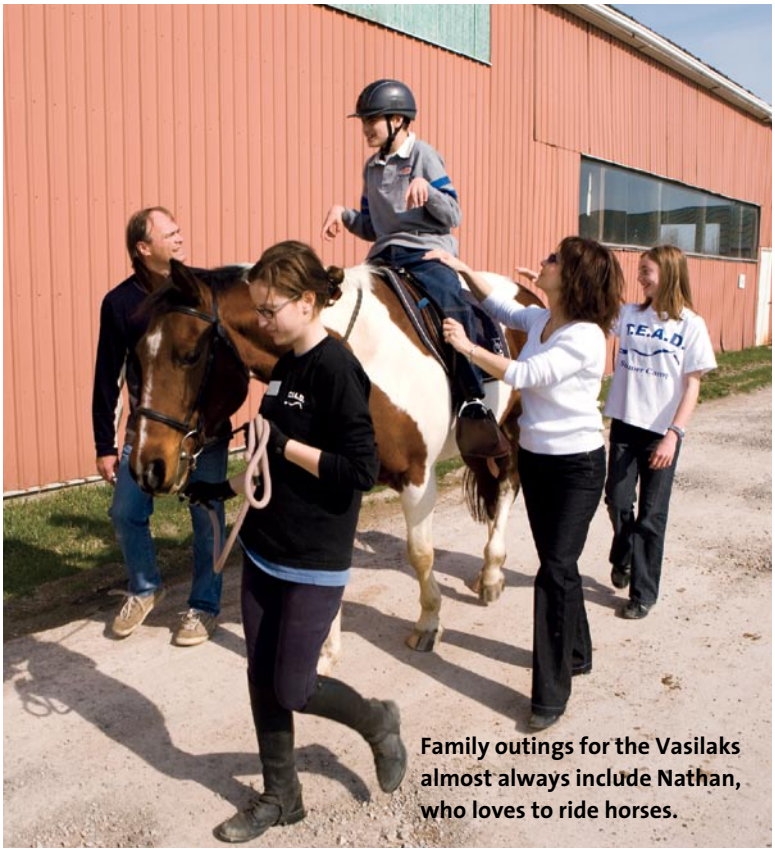
Raising Nathan

My son has a rare genetic defect called Angelman Syndrome, which affects his intellectual development, his speech, even his ability to walk.

BY MARY VASILAK
(AS TOLD TO ANNE BOKMA)

PHOTOGRAPHY BY ROGER YIP



Family outings for the Vasilaks almost always include Nathan, who loves to ride horses.

When I first meet Nathan Vasilak, 17, he greets me with a wide-open smile. He toys with his beloved transistor radio, but his fingers don't have the dexterity to find a music station. His father, John, 57, reaches over and fiddles with it. "He just loves listening to music," says John, as the sound of the Beach Boys singing about California surfing fills the room. Nathan responds excitedly and reaches over to tug affectionately at my arm. Within minutes, he has his head on my shoulder, eyes closed, rocking back and forth to the music. For most people, it takes months to develop this kind of intimacy, but for Nathan, offering instant warmth and physical affection is as natural as breathing.

Nathan, who lives with John, mom Mary, 53, and sister Lindsay, 12, in Ancaster, Ont., has Angelman Syndrome (AS), a rare genetic disorder marked by severe speech, intellectual and developmental delays and an unstable, jerky gait that prevents some children with this condition from ever walking. The disorder, named after Dr. Harry Angelman, who first described it, has often been misdiagnosed as cerebral palsy or autism. Perhaps the most striking characteristic of AS is an angelic disposition. This cheerful demeanour makes children with AS a delight to be around. – Anne Bokma ▶

Nathan Vasilak, seen here with his parents, John and Mary, and his sister, Lindsay, "just loves listening to music."

The first warning sign that something was wrong with Nathan was his failure to gain weight as expected of infants his age. I tried him on the bottle and he still didn't gain weight. Six weeks after his birth at Joseph Brant Memorial Hospital in Burlington, Ont., he was diagnosed with failure to thrive. We didn't know it at the time, but this is a common problem in babies with AS, because some don't have the muscle strength to suck. At six months, Nathan still wasn't making eye contact and couldn't sit up. At 10 months, he began making jerking movements in his sleep, but when I mentioned this to the doctor, he said there was no problem, that Nathan was just having bad dreams.

Later that year, tests showed that he was experiencing seizures and that he had developmental delays. He was put on an anticonvulsant medication, but I didn't get any answers as to what was causing his problems. Over the next few years, he was seen by a few specialists, but there was still no firm diagnosis. Then, when Nathan was four years old, a pediatric neurologist at the Hospital for Sick Children in Toronto who had done research work on AS pinpointed the problem within 20 minutes. The diagnosis was confirmed with genetic testing.

Being told that your son will need supervision for the rest of his life is devastating. Like most parents, we had had high hopes and dreams for our son At first I wondered, why me? I would see other kids doing things my son couldn't do – running and playing at the park. That really hurt. But after spending time at events with other families of kids coping with disabilities, I started thinking, why *not* me? Once you enter the world of disabilities, you see that there are so many people who face – and overcome – huge challenges. You come to understand that nobody is perfect, but everyone has his or her own gifts.

Yes, there are many things Nathan can't do – he can't speak or walk on his own. He may put things in his mouth, so he needs constant and careful supervision; our house and other environments must be child-proofed. But there are plenty of things he *can* do. He goes horseback riding with his dad every Saturday in the spring and fall at the Equestrian Association for the Disabled (TEAD), and in the summer they sail together in a special non-tippable boat. He likes to ride around the neighbourhood in his wheelchair and strum his guitar with his sister.

In his own way, Nathan can tell us that he loves us. He can understand most of what we say as long as we speak in short, simple phrases. If he needs to go to the bathroom or if he's thirsty, he makes certain vocalizations. That's not to say that communicating with Nathan is not at times difficult and frustrating.

More than anything, Nathan loves human contact. He'll play-wrestle with his sister, cuddle with all of us on the couch while we watch TV or simply hold our hands at the dinner table. He has a glowing smile and loves to laugh. He's a great hugger too, and I'm lucky that at 17 he still loves to hug me.

While in many ways Nathan is different than other kids his age, in other ways he's much the same. We've always felt it was important that Nathan be in an inclusive setting, so he has attended the local Catholic school since kindergarten. Every day, he gets on a bus and goes to high school. Educational assistants (EAs) help him in all his classes. In music class, he plays his tambourine. In dance class, his EA moves his wheelchair around while he moves to the beat. In phys-ed class, he works on his special equipment – including a stander and a mat – to stretch his muscles and keep his joints strong and flexible.

Seizures continue to be a problem, and Nathan takes three medications to try to control them. Recently, he started a ketogenic diet that consists of 80 per cent fat and 10 per cent each of protein and carbs. It forces the body to use fats instead of sugar as its source of energy, causing it to produce a substance called ketones. The ketones are supposed to help prevent seizures. The diet has to be rigidly controlled as any deviation can precipitate a seizure. Every day, I calculate Nathan's food down to the ▶

last gram as prescribed by his dietitian. One of the easiest ways to get all the fat into him is to serve him whipped cream with vanilla flavouring and sweetener with sugarless cookies, a dessert he just loves. He's been on the diet for almost a year and after only three months, we were able to withdraw one of his antiseizure medications. Nathan also seems to be more alert and more in tune with his environment since starting this diet and discontinuing the drug.

As is also typical of children with AS, Nathan has a sleep disorder. He wakes up two to three times a night and stays up for half an hour to 90 minutes, depending on his seizure threshold. A nurse comes in three nights a week to settle him when he wakes or to administer medication, and one of us is up with him the other four nights. Sleep deprivation is one of the reasons I left my career as an administrative officer with Environment Canada. I loved my work but couldn't go in every day being sleep-deprived. I also felt I needed to be home for Nathan as his seizure activity increased.

After Nathan's diagnosis, we joined the Canadian Angelman Syndrome Society, the Angelman Syndrome Foundation and the Hamilton Family Network. It was such a comfort to meet other parents of children with AS. I didn't feel so alone, and I could see how rich the lives of these families were, how accepting and full of love they all were. It was like joining another family.

I now help other families of children with a disability learn about advocacy, accommodations in the classroom and how to access appropriate resources. I also speak with student health professionals to give them a parent's perspective on raising a child with disabilities.

When you have a child with a disability, milestone events can be very emotional. I'll never forget how handsome Nathan looked in his beautiful blue gown at his Grade 8 graduation three years ago. I was very proud of him. Yet at the same time, I felt a bit of sadness. I wanted so many things for Nathan, but clearly his future was not going to be like that of the other students; rather, it would be an uncharted adventure.

I sometimes worry about Nathan's future. By law, as can any student in Ontario, Nathan can continue going to school only until he turns 21. After that, it becomes more difficult to provide fulfilling days for people with disabilities. When he's older, Nathan would benefit from funding for an assistant so that he can continue to be engaged in his community. With this kind of help, he could be involved in a small business – maybe dog walking, since he loves animals and the outdoors so much. And with help from such an assistant, Nathan might be able to live on his own.

Nathan has taught our family a lot. John has become much more patient, and Lindsay has learned to stand up for the rights of others. Once, at school, a

boy told her that he wished she was disabled like her brother so he could be mean to her, too. She felt that this was a form of bullying so she went to the principal, who then talked to the bully about his behaviour.

Like any family, ours is always creating happy memories. Every summer, Lindsay and Nathan attend the TEAD horse camp together and we go to Sunday evening concerts in the park near our home. In the fall, it's an annual tradition to attend the Ancaster Fair. And every year, Lindsay and I enter one or two local five-kilometre runs for charity, and Nathan and John cheer us on from the sidelines.

Raising Nathan has strengthened our character and changed our priorities. He has taught us some valuable lessons. One is the importance of relationships – among friends and family – and of unconditional love. Nathan has taught us that someone with disabilities is a person first, a person who has very real gifts to offer the world. ●

CRITICAL GENES MAY BE MISSING

Angelman Syndrome (AS), which affects an estimated one in 15,000 to 20,000 births worldwide, is most commonly caused by a loss or mutation of critical genes on chromosome 15, usually inherited from the mother. A diagnosis, typically made between the ages of one and two years, is based on a history of delayed motor and speech milestones, unusual body movements such as hand flapping, a history of epilepsy and a happy disposition.

When Dr. Harry Angelman, a pediatrician in England, first reported three children with the condition in 1965, many doubted its existence. The first reports of AS in North America didn't appear until the early 1980s; the link to chromosome 15 was discovered in 1987.

There is no cure for AS and little chance for neurodevelopmental improvement, says Dr. Gabriel Ronen, a pediatric neurologist at McMaster Children's Hospital at Hamilton Health Sciences Centre in Hamilton, who treats Nathan. He also notes that parents of kids with AS have a lot of stress and concerns, not the least of which is who will look after their children when they die.

Ronen describes Nathan as a typical AS child: "He's extremely affectionate and very likable," he says. "He really brings his family a lot of love and affection, as do most kids with this condition."